

## **Genetic Enhancement and Prevention of Disability**

**Summary:** This project addresses the ethical issues in genetic enhancement of normal function and in the prevention of genetically transmitted disease and disability.

**Section:** Ethics and Genetics

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**Background:** The advent of the worldwide Human Genome Project in the late 1990s stirred academic, policy, and public interest in many of the ethical issues raised by genetic advances. The initial rationale for the substantial public funding for this project was its potential to increase our understanding of the genetic bases of disease and our ability to prevent or treat disease with a significant genetic component. While there has been only limited payoff to date in treatment of disease, there have been substantial advances in our knowledge of the genetic contribution to many diseases, both single gene disorders and multigenic diseases. With advances in the identification of specific genes that contribute to specific diseases have come in turn tests for the presence of those genes either in carriers or possibly affected individuals. However, treatments have lagged the development of genetic tests for many disorders. Preventive measures have largely been restricted to pre-conception testing of potential parents for their risk of passing on a particular genetic disorder or prenatal testing of an embryo or fetus for the presence of the genes causing, or a risk factor for, the disorder.

The use of genetic tests to prevent disease has been controversial for several reasons. First, prenatal tests for genes associated with serious disease are typically used by parents to identify whether the embryo or fetus will or is likely to have the disease in question, and if the test is positive to terminate the pregnancy. The destruction of embryos and the abortion of fetuses are perhaps the most ethically and politically charged issues in all of bioethics and so it is hardly surprising that they are controversial in this context. Second, and more interesting ethically, has been the critique of genetic testing that has come from the disability community. That critique is complex and varied, but one central theme has been that prevention of disease through genetic testing conflates persons with their disability and sees the person only through her disability. It

fails to distinguish preventing a person from becoming disabled from preventing a person who would be disabled from coming into existence. Since the vast majority of persons with disabilities have clearly valuable and worthwhile lives, the practice of preventing them is seen as stigmatizing of and harmful to people with disabilities, and as ethically unjustified.

A source of longer term broad public concern is the potential for genetic modification and enhancement of normal human traits. There is great scientific uncertainty about the extent to which, much less when, genes making substantial contributions to multigenic behavioral traits will be identified. Further uncertainty attends whether and when genetic modification of such traits will become possible. But the very prospect of significant control over children's genetic inheritance allowing people to select the traits of their children and to enhance normal traits creates a deep uneasiness in many people. This is not unrelated to the widespread opposition to reproductive human cloning. In both cases the opposition to the practices is often powerful while the arguments in support of the opposition remain to be well articulated.

The use of in vitro fertilization combined with preimplantation genetic diagnosis already allows prospective parents some control, such as over its sex, of the genetic character of the embryo that is implanted. Advances in genetics, combined with advances in medicine and pharmacology more generally, have already created the capacity to enhance normal traits with pharmaceuticals. Persons who are not clinically depressed take Prozac and other SSRIs to increase their self confidence, to reduce shyness, and to generally enhance their sense of well being; adults take Ritalin to enhance their ability to concentrate attention to tasks for more extended periods of time; long distance truck drivers and others take Modafil to enable them to function for extended periods of time without sleep. Moreover, there is little doubt that if it becomes possible to enhance other valuable human capacities or traits such as general intelligence or memory or lifespan, whether by genetics or by pharmacology, there will be great public demand for such enhancements. These potential new capacities for enhancing human traits raise deep and not yet well understood ethical issues. How should our ideas about social justice and equality of opportunity change if and when such profound alterations in human nature become possible? Is there some moral significance to the "natural" that underlies popular uneasiness about "playing God"? What are the risks of somatic, much less germ line, interventions to enhance children's traits?

**Objectives:**

1. To assess whether and when there are ethical obligations to use preconception or prenatal genetic testing to prevent genetically transmitted harms to offspring.
2. To assess the disability community's critique of genetic testing that it unjustly discriminates against and harms people with disabilities.

3. To articulate and assess the ethical and policy arguments, both pro and con, about human reproductive cloning.
4. To articulate and evaluate the ethical and policy considerations, both pro and con, about genetic enhancement of human beings.

**Methodology:** This work is primarily conceptual and normative, not empirical, and so the methodology reflects this fundamental difference. It involves articulating and critically evaluating ethical arguments and assumptions concerning the use of genetic information and technology to prevent genetic disease and to enhance normal function.

**Results:** In publications 1 and 10 below, we argued that there is in certain circumstances an ethical obligation to prevent genetically transmitted disabilities and defended this claim against some common objections to it. We also argued for the ethical permissibility of genetic enhancement of humans and evaluated its implications for social justice. In publication 4, I pursued further some of the public policy issues posed by the prospect of genetic enhancement, as well as the use of psychopharmacology for enhancement of normal human functions. In publications 2, 6, and 9, I articulated and assessed the main arguments in support of and against the ethical permissibility of human reproductive cloning. Publications 1 and 3 explored some issues of justice in the access to genetic services.

**Future Directions:** At the present time I plan three principal directions for future work in this area. First, I am at work on a long paper explicitly responding to the critique of the disability community that genetic testing and selection unjustly discriminates in a variety of ways against persons with disabilities. The position I defended on obligations to prevent genetically transmitted harms in an earlier paper published in 1995 and in our 2000 book has received a variety of criticisms from some parts of the disability community and this paper extends my earlier work by systematically addressing and responding to these criticisms. Second, I plan to pursue further the ethical concerns about genetic selection and modification designed to enhance normal human functions in the absence of disease. While there is widespread unease about and opposition to such practices, that unease and opposition has often not been clearly articulated and defended. Since I first wrote on genetic enhancement, there have been significant advances and contributions to the debates (for example, the recently issued Nuffield Council report). I plan in future work to expand and extend my assessment of these issues as the debate evolves. Third, I am at work on a paper on behavioral genetics and equality for an AAAS/Hastings Center project on crafting a public conversation on behavioral genetics. This paper is related to some of the work in our 2000 book, but focuses on advances in behavioral

genetics specifically and some different implications for equality than those we took up in the book.

### **Publications:**

1. Allen E. Buchanan, Dan W. Brock, Norman Daniels and Daniel Wikler, From Chance to Choice: Genes and Social Justice Cambridge: Cambridge University Press, 2000. \_\_\_\_Forthcoming in Chinese, Italian, and Spanish language editions.
2. "Cloning Human Beings: An Assessment of the Ethical Issues Pro and Con," in Cloning Human Beings Volume II: Commissioned Papers. Rockville, MD: National Bioethics Advisory Commission, 1997.  
Reprinted in shortened version in Clones and Clones, eds. Martha Nussbaum and Cass Sunstein. New York: W.W. Norton & Co., 1998.  
Reprinted in: Cloning and the Future of Human Embryo Research, ed. Paul Lauritzen. Oxford: Oxford University press, 2000.
3. "Access to Genetic Services," in Genome Horizons: Public Deliberations and Policy Pathways: Conference Proceedings. University of Michigan, 1998, 40-42.
4. "Enhancement of Human Function: Some Distinctions for Policy Makers," in Technologies for the Enhancement of Human Capacities, ed. E. Parens. Washington DC: Georgetown University press, 1998.
5. Dan W. Brock and Allan E. Buchanan, "The Genetics of Behavior and the Concepts of Free Will and Determinism," in Genetics and Criminality, eds. J. Botkin, W. McMahon & Leslie Francis. Washington, DC: American Psychological Association, 1999.
6. "Cloning, Ethics," in Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology. 2000.
7. "Implications of Genetics for Concepts of Disease," in Genetics in the Clinic, eds. M. Mahowald, T. Aspinwall, V. McKusick and A. Scheuerle. Philadelphia: Moseby, Inc. 2001.
8. "Genetics and Confidentiality," American Journal of Bioethics 1, 3 (2001) 34-35.
9. "Human Cloning and Our Sense of Self," Science 296 (April 12, 2002) 314-316.
10. "Genetic Engineering," in Companion to Applied Ethics eds. Ray Frey and Christopher Wellman. London UK: Blackwells Publishers, forthcoming 2002.